Seema Verma, Administrator  
Centers for Medicare and Medicaid Services  
Hubert H Humphrey Building  
200 Independence Ave, SW  
Washington D.C. 20201

Dear Ms. Verma:

As members of the Wisconsin delegation, we want to thank you for your openness to working more closely with the States in the implementation of the home and community based services (HCBS) rules and related guidance (“Settings Rule”). In doing so, we also urge CMS to amend the Settings Rule and guidance so that individuals with disabilities receiving Medicaid waiver funding will have a right to choose the residential, employment, and day habilitation setting that best meets each individual’s needs and abilities.

In order to maximize opportunity for people with the most significant disabilities, CMS should amend the Settings Rule (42 C.F.R. § 441.301(c)) to (a) make clear that an individual’s right to choose where to live and receive services is paramount; and (b) eliminate the presumption that settings specifically designed to serve individuals with intellectual or developmental disabilities are “isolating” and therefore subject to a higher standard to qualify for waiver funding (see subparagraph 441.301(c)(5)(v)). Furthermore, CMS should eliminate or clarify language that attempts to limit choice and thus opportunities for people with disabilities. See, e.g., 441.301(c)(2)(i) (stating that the setting in which an individual resides must be by their choice but then attempting to restrict the menu of settings). CMS can strike the offending language or recognize that intentional communities for people with disabilities are not isolating or segregating, but rather can be an excellent choice for individuals.

Across the United States, there are intentional communities for people who are: (a) over the age of 55, (b) retirees, (c) seniors, (d) and military veterans. Some variation of these and other types of intentional communities are in every state receiving federal support, yet no government entity calls them isolating or segregating. Rather, these intentional communities are considered part of their communities. An intentional community that would allow people with disabilities to live in an environment designed to accommodate many of their special needs, however, would not be considered part of the community under the Settings Rule absent having to prove itself by heightened scrutiny. Such a narrow interpretation of a proper setting is both counterintuitive and counterproductive. Let people live and work where they will thrive. Let choice mean choice.

The same is true for work settings. People with disabilities live in the real world and have a right to choose a job that meets their needs. Many choose to work at work centers run by community rehabilitation providers. Community rehabilitation providers exist in communities
across the country. They provide jobs, skills-based training and work experience, job coaching, life-skills training, and assistance in expanding employment opportunities for people with disabilities. These nonprofit agencies were the community solution to bringing people with significant disabilities out of institutions and helping individuals with disabilities live full and robust lives. For more than 50 years, community rehabilitation providers did much of the hard work in respect to creating programs and opportunities for people with significant disabilities, but for some reason, CMS has deemed work centers run by community rehabilitation providers to be settings outside the community. This is wrong. Community rehabilitation providers are an integral part of their communities.

We fully support the goal of community integration for individuals with intellectual and developmental disabilities, but the presumptions the Settings Rule makes about community interaction are inaccurate. Rather than helping people with disabilities, the Settings Rule puts at risk programs in Wisconsin with a long history of providing the highest quality of care for individuals with intellectual or developmental disabilities. Unfortunately, individuals that have chosen these programs because they best meet their needs will be forced into workplace settings that are not equipped to provide the necessary support and workforce development that these individuals historically have been afforded.

We feel strongly that the Settings Rule should be modified to eliminate the presumption against intentional communities, work centers, campus settings, farmsteads, and other residential, work, and day programing options (including prevocational services) designed to serve individuals with intellectual or developmental disabilities. We support an individual’s right to live in the environment that is best for that individual. We support an individual’s right to work in work centers in accordance with their person-centered plan or if unable to achieve their competitive integrated employment goal. In other words, we support the right of people with disabilities to choose from the complete menu, not the limited menu that exists under the Settings Rule.

CMS should not favor one quality setting over another or interfere with an individual’s right to choose where they wish to live and work. Indeed, the federal government should be focused on increasing the quality options available to individuals with intellectual or developmental disabilities, rather than restricting those options. It is vital that we keep a full array of options available to people with the most significant disabilities. This can only be done by amending the Settings Rule and issuing new guidance expanding the universe of acceptable settings for residential, employment, and day habilitation choice.

Thank you for your attention to this matter and we look forward to hearing from you in the coming weeks.

Sincerely,

Glenn Grothman  
Member of Congress

F. James Sensenbrenner, Jr.  
Member of Congress